

APPENDIX 2. DESCRIPTION OF PGHD UTILISATION HEALTH EFFECTS INCLUDING EXAMPLE QUOTES

The quotes presented below have been cleaned for readability. For instance where words or syllables are repeated, the duplicates are removed, e.g., “to remind you, is g- is gonna help” became “to remind you, is gonna help”. Fillers such as ‘um’ or ‘yeah’ have also been removed. Quotes from the Melbourne health service stroke survivors are marked with ‘AHP’, and the quotes from the Headway stroke survivor is marked with ‘HWC’.

Theme	Stroke Survivors	Clinicians
Health-Related Behaviours	<p>Most of the stroke survivors from the Melbourne health service (‘Site 1 survivors’) shared that seeing their progress through their PGHD could potentially encourage them to “keep going” (INT2_AHP), and “to do more” (FG1_AHP_2) of their rehabilitation exercises. Although they would not “rely on it” (INT1_AHP), they would use the rehabilitation system “more and more” (INT1_AHP) because they “can see it’s helping” (INT2_AHP). Frequency of PGHD access may also help, because PGHD “that keeps popping up in front of you, to remind you, is gonna help” (INT2_AHP). They also felt that PGHD may help them know their movement mistakes, so they “can know to correct yourself” (INT2_AHP).</p> <p>It may be important for the PGHD to be positive, however. As one survivor put it, “As long as your numbers are going up, it just keeps you positive and keep going” (FG2_AHP_1). Conversely, two survivors described how low PGHD would indicate that the system was not helping with their rehabilitation, and therefore they would be less inclined to continue using it; unless there was “some explanation of something that you need to consider looking” (INT2_AHP). If they felt they did not perform an exercise as well as their resulting PGHD showed, they would “probably lose faith in the system” (INT2_AHP). Finally, a few survivors felt that PGHD would likely have “no effect” (FG1_AHP_1) on their health behaviour. Another indicated that PGHD would not encourage any behavioural changes with their activities of daily living (ADL).</p>	<p>On the other hand, clinicians mainly anticipated that PGHD would be potentially encouraging for stroke survivors, but for slightly different reasons. PGHD would inform survivors of “the quantity or the amount they’ve exercised, so that might stimulate them to be more compliant” (FG3_AHC1_5) because of the sense of “accountability” (FG3_AHC1_2, FG3_AHC1_4) it would give them. Moreover, clinicians thought that survivors might be more compliant because they better “understand the purpose and the reason why they’re doing”(FG3_AHC1_5) the exercises. However, clinicians agree that negative PGHD, especially if it’s consistent, would be discouraging: “They might get over it, or might not be willing to participate” (FG3_AHC1_3).</p>

Theme	Stroke Survivors	Clinicians
Feelings about health status	<p>A Site 1 survivor mentioned that seeing health progress through their PGHD is “a big thing, that’s a mental thing” (INT1_AHP) because seeing “yourself gradually making improvements, it just makes you feel so much better. Okay, I’m achieving something” (INT1_AHP). Seeing progress could potentially provide a feeling of accomplishment: “at least you could look back and say ‘Hang on, last week I was only doing it at half the pace’” (INT1_AHP). The Site 2 survivor agreed, describing how seeing her progress made her feel “upbeat” and “satisfied”: “I just like seeing them. ‘Cause it makes me feel good” (INT1_HWC1). PGHD could potentially make stroke survivors more “confident” (INT1_HWC1): “if your numbers are improving, you’re getting better, more confident” (FG2_AHP_1). “It just gives you confidence” (INT1_AHP).</p> <p>On the flip side, PGHD could potentially raise feelings of disappointment and confusion. If their PGHD indicates that they’re “not improving” (FG2_AHP_1), that they’re “going backwards, that would be, a little bit depressing” (INT1_AHP). As the Site 2 survivor put it: “I don’t like not doing well” (INT1_HWC1). A mental health comorbidity might increase the potential of this happening: “if someone was really, mentally depressed that would, geez, you know, ‘I’m not getting anywhere’” (INT1_AHP). Moreover, a mismatch between how they felt they performed and what their PGHD was showing could make them feel dejected: “you probably think oh, the system’s not doing its job” (INT2_AHP).</p> <p>Simply seeing percentages at the end of an exercise, as is the case with Jintronix, might also cause confusion: “I’m thinking well, are normal people at a hundred percent? And I’m only at 60? So the percentages to me is more difficult to understand. [...] I mean, are we trying to be a hundred percent at these things?” (FG1_AHP_2).</p> <p>Some stroke survivors also reported potentially feeling self-awareness about their health through PGHD, because it allows</p>	<p>Clinicians shared the same perspective, that progress might provide “satisfaction” (FG3_AHC1_1): “Everybody likes to get a score, I feel. And a score can motivate you or please you” (FG3_AHC1_5). A clinician noted that survivors’ increased confidence could be relevant to when they are “out on the community” (FG3_AHC1_4).</p> <p>Clinicians agree that simply providing percentages to survivors at the end of an exercise could cause “confusion” (FG3_AHC1_2, FG3_AHC1_1), because they may not “understand” (FG3_AHC1_1) what their PGHD mean; thus there may be “scope to put in [the PROM-PGHD] something about, I didn’t really understand” (FG3_AHC1_4). Additionally, clinicians think that PGHD might cause some to doubt the effectiveness of the system: “I’m doing better with my therapy, they don’t say I’m doing better with my walking, because I’m being better with my Jintronix” (FG3_AHC1_4).</p> <p>Two clinicians also thought that some survivors might feel indifferent, “because, the data doesn’t specifically relate to their goals” (FG3_AHC1_2), then “some people, it wouldn’t worry them” (FG3_AHC1_4).</p>

Theme	Stroke Survivors	Clinicians
	<p>them “to measure your improvement or your deterioration. [...] You could see it in cold hard figures.” (FG2_AHP_2). PGHD would help them them understand “if you’re improving each day” (FG2_AHP_1), so they can see if they’re “heading in the right direction” (FG2_AHP_1). However, one survivor didn’t think PGHD would provide that sense of awareness: “we all know what we have to do, but we can’t do it” (FG1_AHP_1).</p> <p>Meanwhile a Site 1 survivor felt indifferent towards PGHD, because it’s how they feel about doing their activities that matter. PGHD could also elicit different emotions at different times: “maybe one day I felt okay, and the next day I felt blue and sad” (INT2_AHP).</p>	
New theme: relationship with family and carer/s	<p>A few Site 1 survivors shared that they could potentially be compelled to “share” their PGHD with family “to keep them included in my state of health” (FG1_AHP_2). PGHD might help them in describing their progress to family: “you could show them something, it’s easier for them to visualize”; especially when they get “fatigued” and they’re “trying to explain something and” they “run out of words” (INT1_AHP). Sharing positive PGHD with family could be a pleasant experience: “it’s building you up” (INT1_AHP). However, the Site 2 survivor and some Site 1 survivors would “not really” (FG1_AHP_1) be prompted and “wouldn’t bother” (INT2_AHP) to contact loved ones.</p>	<p>Clinicians agreed that stroke survivors can “share it [PGHD] with family. [...] It’s that chance to, bragging power as well, perhaps” (FG3_AHC1_4). It might help older survivors to connect with younger family members: “especially with the younger generation, they’re so tech-savvy and it engages them” (FG3_AHC1_1).</p>
Interest in care processes	<p>Site 1 survivors indicated that it would be beneficial seeing rehabilitation progress through their PGHD, because it would help them know whether that system “was working, and all your effort was worthwhile” (FG2_AHP_2). They liked seeing it because “any information is gonna help you understand the process you’re under” (INT2_AHP), to see if they’re “improving each day” (FG2_AHP_1). The Site 2 survivor shared a similar experience: “I like to see the base level I was at, and what I’ve achieved” because</p>	<p>The sentiments of stroke survivors were strongly reinforced by the clinicians. Stroke survivors would potentially “understand better [their rehabilitation progress] after a second session where they could compare their results. [...] It’s good for them to have a comparison, to see how they’ve changed from one session to [an]other one” (FG3_AHC1_5). Survivors “could see change” (FG3_AHC1_2, FG3_AHC1_3) and their “improvement” as a result of performing the exercises, and they may even want to “share it with family” (FG3_AHC1_4).</p>

Theme	Stroke Survivors	Clinicians
	<p>“it helped me understand my rehabilitation progress” (INT1_HWC1). It could be better than relying on clinician’s feedback, which could be “very slow, and quite often you’re bound by what they tell you. [...] If I wanted to sort of look at one detail straight away, it could, quite often be quite hard to get them to tell me. Whereas here, I can just look at it” (INT1_AHP).</p> <p>Stroke survivors also described how PGHD could potentially increase their interest in knowing their therapy status: “the summary can give us uh, more of a picture of the progress that we’ve made” (FG1_AHP_2). More importantly for a survivor, it could help them know “how far I’ve got to go”, based on their “limitations” (INT1_HWC1). “With repetitive sort of exercises, [...] you’re trying to not to, let that go berserk, if you’re exerting yourself too much” (INT1_AHP). This is necessary for self-management of energy: “Do I need to save my energy, or [...] I can go for it?” (INT2_AHP).</p> <p>For one survivor, however, “it’s not vital”, although “it would be of interest” (FG1_AHP_2); and for another “it doesn’t interest” (FG2_AHP_1) them at all. Interest might also change over time: “initially, you may be concerned to get the information, ‘cause people asking you, how are things going, what are you doing”, but later that “sort of detail becomes less and less important” and what matters is “the end, am I going okay, I’m not going, is my treatment going to change, or is it staying the same? That sort of level” (INT2_AHP).</p> <p>PGHD would also be a form of “feedback” (INT1_AHP) to inform survivors where they’ve done well: “I want to know how well I’m going” (INT1_HWC1), but also what they need to do better. “It’s always nice to see when you’ve done things right, but quite often you learn more when you’ve done something wrong” (FG2_AHP_2). PGHD helped the Site 2 survivor understand “what movements I had to do” (INT1_HWC1).</p>	<p>Clinicians also believed that survivors would be more interested in how PGHD could have “positively impacted [...] your ADL like your achievement of your goals than anything else” (FG3_AHC1_2), i.e., if it had “any relevance to a functional activity. You know like washing the dishes, or hanging the washing out or climbing a flight of stairs” (FG3_AHC1_4). Clinicians “try to make [their] therapy goal-focused” (FG3_AHC1_1), and PGHD could potentially help survivors understand how the exercises related to their “goals” (FG3_AHC1_1): “Improve my walking, or improve my balance [...] or reduce my falls risk” (FG3_AHC1_5). In fact, it may not be “functionally relevant” (FG3_AHC1_4) to them otherwise. Thus “one question [in the PROM-PGHD] could be, I could understand the purpose of the exercise in my recovery, I wasn’t sure” (FG3_AHC1_5), to “judge whether or not this [exercise] is working for the patients” (FG3_AHC1_2). However, one clinician thinks that “even if they didn’t fully understand the data I think they’d still like to see, something” (FG3_AHC1_2).</p> <p>Two physiotherapists agreed that PGHD could help survivors understand how they’re performing, because PGHD could give “some knowledge of performance” (FG3_AHC1_2). Clinicians agree that PGHD could affect survivors’ sentiments about the care they receive: “if you just did the computer thing and they [...] just stopped without data they’d be like, why do I do it?” (FG3_AHC1_2) “Why do it? Why all this?” (FG3_AHC1_4)</p>

Theme	Stroke Survivors	Clinicians
	<p>Finally, PGHD could potentially affect Site 1 survivors' sentiments about their care: "everything is open and clear and there's nothing going on in the background about anyone judging me or you know, just what what has happened is easy for me to see, and that there isn't anything that's being kept from me" (FG1_AHP_2). However this trust could vary: "As I go through it, I thought about it, it also depends on where the data is going" (FG1_AHP_1).</p>	
Personal care goals	<p>Seeing PGHD "encouraged" the Site 2 survivor "to try harder": "I get a score. And, I have to improve my score, each time. I try to", even "if I wasn't doing well, I would work harder" (INT1_HWC1). Some Site 1 survivors shared that PGHD could potentially affect them in a similar way: "if it didn't match up [to] what I thought I should be doing it means I would have to try harder" (FG2_AHP_2). A survivor would likely want "to improve it, you'd try your best" (FG2_AHP_1).</p>	<p>Some clinicians agreed that PGHD could potentially encourage stroke survivors: "it doesn't have to be too detailed or complex, but just something to show..Today I got 50%" (FG3_AHC1_3) to give them "something to keep striving" (FG3_AHC1_3) and to "motivate" or "please" (FG3_AHC1_5) them. One clinician, however, thought that "some people, it [PGHD] wouldn't worry them" (FG3_AHC1_4).</p> <p>Finally, a clinician didn't think that PGHD would help survivors "form new goals based solely on that data without like liaising with their therapist" (FG3_AHC1_2), although one survivor felt that "Yeah it might" (FG2_AHP_2).</p>
Relationship with care provider/s	<p>After seeing her PGHD, the Site 2 survivor was prompted to ask her therapist, to ask "what could I do better" (INT1_HWC1). Most Site 1 survivors agree that PGHD could potentially prompt them to contact their clinician: "if it's sort of, at left field [...] or it's at odds to what I think I'm doing, I thought I was doing all right, but I'm obviously not, so what do I gotta do" (INT2_AHP), "what are we doing now?" (FG2_AHP_1) One survivor would even question the treating clinician: "I'd say to the therapist, what are you doing wrong, 'cause I know I'm not doing anything wrong" (FG2_AHP_2).</p> <p>Interestingly, if their PGHD is better than how they felt they did, it could potentially prompt them "next time you saw [the clinician] you'd say, I don't think this is quite all right" (INT2_AHP). For one survivor, however, seeing the PGHD would not "be the instigator of seeking more help" (FG1_AHP_2). There was also some interest</p>	<p>The clinicians agreed that stroke survivors would potentially be prompted to ask them why they did "so badly? How can I get a better score, why did I not do very well" (FG3_AHC1_4), and "can I do something more differently" (FG3_AHC1_5). Some clinicians also agreed that survivors would "ask for more explanation" (FG3_AHC1_5) "where [the] score [had] come from", and "to explain things more" (FG3_AHC1_4) how their PGHD would affect their progress.</p> <p>While a Site 1 survivor felt that seeing their PGHD could potentially help them understand why their exercises were prescribed to them, clinicians thought that survivors would need to talk to them in order to understand their therapy better. "They might not really, grasp the concept of that I think. They'll need a bit more of education" (FG3_AHC1_3). Additionally, some clinicians felt that if survivors know their PGHD, "the quantity or the amount they've exercised, so that might stimulate them to be more compliant" because it promotes "accountability" (FG3_AHC1_2, FG3_AHC1_4). It might be similar to doing "homework"; "maybe if</p>

Theme	Stroke Survivors	Clinicians
	<p>with “what happens” to their PGHD: “where is it going, what's it going to be used for?” (FG1_AHP_2) While another survivor would be prompted to ask if they're “making progress”, and if their clinician is “happy with my progress” (INT1_AHP).</p> <p>A Site 1 survivor also felt that seeing their PGHD could potentially help them understand why their exercises were prescribed to them, i.e., “just [to] keep you motivated” (FG2_AHP_1).</p>	<p>they're not being compliant, they might get a phone call from the therapist” (FG3_AHC1_5).</p>